University of Alberta

Treatment Expectation of Parents whose Children are Referred to a Pediatric Chronic Pain Clinic

By

Kathleen Louise Reid

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of

Master of Nursing

Faculty of Nursing

Edmonton, Alberta

Fall, 2008

Library and Archives Canada

Published Heritage Branch

395 Wellington Street
Ottawa ON K1A 0N4
Canada

Bibliothèque et Archives Canada

Direction du Patrimoine de l'édition

395, rue Wellington
Ottawa ON K1A 0N4
Canada

Your file Votre référence
ISBN: 978-0-494-47174-6
Our file Notre référence
ISBN: 978-0-494-47174-6

NOTICE:
The author has granted a non-exclusive license allowing Library and Archives Canada to reproduce, publish, archive, preserve, conserve, communicate to the public by telecommunication or on the Internet, loan, distribute and sell theses worldwide, for commercial or non-commercial purposes, in microform, paper, electronic and/or any other formats.

The author retains copyright ownership and moral rights in this thesis. Neither the thesis nor substantial extracts from it may be printed or otherwise reproduced without the author's permission.

AVIS:
L'auteur a accordé une licence non exclusive permettant à la Bibliothèque et Archives Canada de reproduire, publier, archiver, sauvegarder, conserver, transmettre au public par télécommunication ou par l'Internet, prêter, distribuer et vendre des thèses partout dans le monde, à des fins commerciales ou autres, sur support microforme, papier, électronique et/ou autres formats.

L'auteur conserve la propriété du droit d'auteur et des droits moraux qui protège cette thèse. Ni la thèse ni des extraits substantiels de celle-ci ne doivent être imprimés ou autrement reproduits sans son autorisation.

In compliance with the Canadian Privacy Act some supporting forms may have been removed from this thesis.

While these forms may be included in the document page count, their removal does not represent any loss of content from the thesis.

Conformément à la loi canadienne sur la protection de la vie privée, quelques formulaires secondaires ont été enlevés de cette thèse.

Bien que ces formulaires aient inclus dans la pagination, il n'y aura aucun contenu manquant.

Canada

Dedication

I dedicate this thesis to my wonderful loving supportive family, **Graham, Caitlin and Geoff.** Taking on a Master's degree in my 40's was tough and you were all wonderful to help me get through it. **Graham**, you encouraged me to go back to school, knowing it was something I always wanted to do. You supported me in so many ways beyond just the financial! **Caitlin and Geoff,** you understood the amount of time it took for me to get through this. And together, you all assisted me in so many ways – learning to cook and clean, giving up a few family vacations and sacrificing the salary so that I could complete my dream. I hope that you have all seen that higher education is possible no matter how old you are!

"Apply yourself. Get all the education you can, but then do something. Don't just stand there, make it happen"

Lee Iacocca

Abstract

I reviewed the literature on treatment expectations of parents whose children have chronic pain and one of the conclusions was the need for a study to explore their treatment expectations prior to being seen in a Pediatric chronic pain clinic. Using a paper-based survey I developed based on the literature and reviewed by clinical experts I completed a pilot study into the treatment expectations of parents whose children were referred to the Pediatric Chronic Pain clinic at the Stollery Children's Hospital. Fourteen parents completed the survey. All parents desired more information about the causes of their child's pain, treatment options, ways to cope with the pain, and the effects of pain on both body and mood. Most parents ranked each of the various treatment options as important for their child and in particular, indicated it was very important to have the pain team 'be there' for them.

Acknowledgements

First, I would like to thank my supervisor Dr. Janice Lander and my thesis committee members, Dr. Bruce Dick and Dr. Shannon Scott. Each of you provided me with support, encouragement, and feedback through the months it took to complete my thesis. You read my drafts, answered my many questions, and encouraged me to think in different ways. I would like to thank you all for your hard work and dedication. I am sure there were days when you didn't want to answer that phone or open that email when my name came up, but you did answer anytime I asked and for that I am truly grateful.

I would like to thank the management at the Stollery Children's Hospital in Edmonton for allowing me the time to work on my thesis, allowing me access to the families for my research, and supporting me in completing my degree. I would also like to thank the staff in the pediatric surgical clinic who assisted me by handing out and collecting the surveys.

I would like to thank Tracy Hyndman, RN, MN at the Complex Pain Clinic, Alberta Children's Hospital in Calgary for providing me with the idea for the research project, for reviewing the questionnaire, and for moral support along the way.

Finally, I would like to thank the parents, mostly moms, who took the time to complete the survey while waiting for their appointment. I am very aware that raising a child who suffers from chronic pain is a difficult journey for you, and know that asking yet one more thing of you is at times a burden. You completed the survey, knowing that the information you provided would not necessarily help

your child, yet you did it so that we can help other children in the future. Throughout this process I always remembered the words of Bernie Carter who wrote an editorial titled "If I have to say it one more time, I swear I'm gonna kill someone". She talked about how many times parents need to repeat their stories, how often they do not feel as if they are being listened to. I know that for the children and families who came to the pain clinic, they had probably encountered professionals who had not listened; who did not believe their child had chronic pain, or just did not know how to help them. I knew that asking you to fill in "one more form" while waiting to see yet another health care team, may have made you sigh, may have caused you stress, may have perhaps made you think "why am I here?". Yet fourteen of you chose to complete it and for that I thank you.

TABLE OF CONTENTS

INTRODUCTION **1**
- BACKGROUND 1
- PURPOSE 2
- MANUSCRIPT OVERVIEW 2
- GENERAL DISCUSSION OVERVIEW 3
- APPENDICES OVERVIEW 3

TREATMENT EXPECTATIONS OF PARENTS WHOSE CHILDREN ARE REFERRED TO A PEDIATRIC MULTIDISCIPLINARY PAIN CLINIC **4**
- ABSTRACT 5
- BACKGROUND 6
- METHODS 8
  - Sample 8
  - Procedures 9
  - Measures 9
- RESULTS 10
  - The need for information 10
  - Chronic pain treatment options 10
- DISCUSSION 11
- CONCLUSIONS AND FURTHER DIRECTIONS 15
- REFERENCES 19

GENERAL DISCUSSION **26**
- RESEARCH TOOL 26
- SAMPLE 27
- STUDY DESIGN 27
- CONTRIBUTIONS, LIMITATIONS AND FUTURE DIRECTIONS 29
  - Contributions 29
  - Nursing Implications 30
  - Health Care Implications 31
  - Future Directions 32
- REFERENCES 33

APPENDICES
- Appendix 1: Treatment Expectations of Parents Whose Children are Referred to a Pediatric Chronic Pain Clinic: Literature Review 35
- Appendix 2: Survey and Parental information Letter 51

LIST OF TABLES

Table 1: Demographic Data 16
Table 2: How important is it to receive information about chronic pain..... 17
Table 3: How important is each pain treatment..... 18

Introduction

This thesis is an outcome of a masters program of research into treatment expectations in parents of children with pediatric chronic pain. The purpose of this research was to explore the treatment expectations of parents presenting for their first visit with their child to a multidisciplinary pediatric chronic pain clinic. This thesis is written in the style of a paper-based thesis and consists of an introduction, a manuscript, a general discussion, and a literature review paper, located in the appendices.

Background of the Study.

I am a Nurse Practitioner, working in the Pediatric Chronic Pain Clinic at the Stollery Children's Hospital, Edmonton Alberta. We opened our clinic in March 2008. In preparing to open our clinic, I was interested in learning more about the information needs of the children and family who would be referred to our clinic. I read extensively about chronic pain in children, and realized that very little research had been conducted into treatment expectations prior to clinic visits. While a growing body of literature ties treatment expectations to treatment success in the area of chronic pain management for adults, little is known about this area in children. I knew that many forms of information are available to families – books, the Internet, self-help groups, and professional advice, but wanted to explore further which of these areas would be important to the families of children with chronic pain. I therefore decided to explore their treatment expectations and preferred methods of receiving treatment information.

Chronic pain in childhood is common, and severe debilitating chronic pain affects many aspects of the lives of both the child and the family. The

biopsychosocial approach to pediatric chronic pain is effective if parents and children understand it, and agree to address the multiple domains involved in chronic pain. Children and families seen in pediatric chronic pain clinics are often frustrated from dealing with the pain and disability, and with the health care system, which, while searching for a cause, has often not addressed the management of the pain. By the time they are referred to a pain clinic, they may have many misconceptions about pain and do not know what to do to manage the pain and disability.

It is important to understand what expectations parents have of the clinic visit in order to determine their understanding of chronic pain, their willingness to accept various treatment options for their child, and to ensure that appropriate services are in place to meet both parental and child needs. It is often the parent who decides whether to bring the child to a clinic, and whether to follow through with treatment recommendations. Therefore, the purpose of this descriptive study was to explore the treatment expectations held by parents for their first visit to a pediatric multidisciplinary pain clinic.

Manuscript I

The theoretical framework that guided this study was drawn from Palermo and Chambers' (2005) integrative model of parent and family factors in pediatric chronic pain and associated disability. This model examines how individual, dyadic and family level variables influence children's pain and disability. Each of these variables influence pain and affect the degree of functional disability associated with pain.

Fourteen parents, the majority mothers, completed a paper-based survey exploring their information needs and treatment expectation prior to their first visit to our clinic. The majority of the children experienced pain on a

daily basis, for at least two years. Many had seen at least two health care providers for the pain. Half of the children had more than one pain diagnosis or site, with a third indicating their child experienced headache, abdominal pain, and muscle pain. All parents desired information about the causes of their child's pain, treatment options, ways to cope with the pain, and the effects of pain on both body and mood. Most parents ranked each of the various treatment options as important for their child, and, in particular, indicated it was very important to have the pain team be there for them. Parents ranked reading materials about chronic pain as important. It was less important to have other parents be there for them.

General Discussion

This section consists of a general discussion of the issues associated with the research, how the findings contribute to existing research, their relevance for nursing, as well as suggestions for further research.

Appendices

The first appendix includes a review of the literature regarding parental treatment expectations in chronic disease in general and specifically regarding parental treatment expectations for pediatric chronic pain. The second appendix includes the study survey tool and parent information letter.

Treatment Expectations of Parents Whose Children are Referred to a Pediatric Multidisciplinary Pain Clinic

Kathy Reid, RN, BScN[1]

Dr. Janice Lander, RN, PhD[1]

Dr. Bruce Dick, PhD[2]

Dr. Shannon Scott, RN, PhD[1, 3]

1. Faculty of Nursing, University of Alberta, Edmonton AB
2. Faculty of Anaesthesiology and Pain Medicine, , University of Alberta, Edmonton AB
3. Department of Pediatrics, Faculty of Medicine and Dentistry, University of Alberta, Edmonton AB

Abstract

Background: Chronic pain in childhood is increasingly being recognized as a significant clinical problem. Chronic pain treatment at a multidisciplinary pain clinic involves different approaches. It is important that parents understand the different treatment options in order for treatment to be successful in increasing function and improving quality of life.

Objectives: To explore the treatment expectations held by parents for their first visit to a pediatric multidisciplinary pain clinic.

Methods: Fourteen parents completed a paper-based survey exploring their treatment expectations immediately prior to their first visit to the pediatric pain clinic.

Results: All parents desired information about the causes of their child's pain, treatment options, ways to cope with the pain, and the effects of pain on both body and mood. Most parents ranked the various treatment options as important for their child. All parents indicated it was very important to have the pain team be there for them.

Conclusions: These findings indicate that parents want more information about chronic pain and treatment options. Pediatric chronic pain clinics have the ability to assist children with chronic pain and their families considerably by providing information about chronic pain and the various treatment options available to them.

Treatment Expectations of Parents whose Children are Referred to a Pediatric Chronic Pain Clinic

Chronic pain in childhood is increasingly being recognized as a significant clinical problem that affects multiple domains of the lives of both the child and the family. Epidemiological studies have shown that chronic pain in childhood affects between 15 – 39% of children (1-3). Headache is the most common chronic pain complaint expressed by children, followed by abdominal pain and musculoskeletal pain (4). Up to 50% of children who report chronic pain indicate multiple sites, most commonly headache and abdominal pain (5). For most children, chronic pain is not debilitating in the long term. However, for a small percentage of children, the pain can be severe and disabling, leading to the development of "pain associated disability syndrome", a syndrome characterized by severe difficulties with functional abilities regardless of the location or cause of the pain (6). Affecting between 1 – 3% of the general pediatric population, these are the children who are most likely to be referred to a pediatric multidisciplinary pain clinic (4).

Children and adolescents with chronic pain may experience decreased confidence in their ability to function, increased physical vulnerability to pain, increased somatic symptoms, depression, and higher anxiety (7, 8). Children and adolescents with unexplained chronic pain often report impairment in sports activities, school absences, limitations in social functioning, and sleep disturbances including nocturnal wakening (9, 10). They also often report that pain controls their lives and prevents them from living a normal life (11).

Parents of children with chronic pain also suffer. For instance, they report increased levels of depression, anxiety and parenting distress (12, 13), and restrictions in their own social activities (14). Parents of children with chronic pain may face challenges adjusting to acceptance of pain due to pain catastrophizing, which is thinking that pain is a sign of impending health catastrophe. Parental catastrophic thinking about pain contributes to pain associated disability in the child with chronic pain (15, 16).

As chronic pain has an impact on many dimensions of the lives of both the child and family, a multidimensional approach to treatment is required. The biopsychosocial approach to chronic pain management attempts to address the many dimensions involved. This approach addresses the biological basis of pain, the psychological interventions that assist the child and family to understand and cope with the pain and its consequences, and alters the responses to pain, and the social factors affected by the pain, such as school and other activities (17 - 19). A multidisciplinary approach involving pharmacological management, physical therapy and psychological intervention to assist the child and family to manage the pain and reverse the disability has been found to improve functioning and the child's wellbeing (20 – 27). There is good evidence that psychological treatments, including relaxation and cognitive- behavioral therapy are effective for certain chronic pain conditions in children but more research is needed (28 - 32).

Dedicated pediatric chronic pain clinics have been established to assist children and their families in managing disabling chronic pain but only five such clinics exist in Canada. These clinics, located in major urban areas, each see only between 30 – 80 new referrals annually (33).

Few studies have addressed the treatment expectations of parents and children with chronic pain. By the time a child and family are seen in a multidisciplinary pain clinic, they have often seen many specialists and are suffering from 'referral fatigue'. For some parents, a firm diagnosis has not been provided and they are still searching for an organic reason for their child's pain (34). When asked prior to attending a pain clinic what they thought would be the most helpful outcome, parents cited learning to cope with the pain and learning to manage stress. However, a significant number of parents reported that they did not know what to do for the pain, and that current therapies for pain were not effective for their child (35). Research into treatment expectations for complementary therapies in managing chronic pain in children has shown that parents rated complementary approaches as more likely to be helpful than their children did, but that the expected benefits from both complementary and conventional treatments was low for both parents and children (36).

It is important to examine pain and its associated disability within the context of the parent-child relationship. Understanding the treatment expectations of parents will add to the growing knowledge base of factors associated with pediatric chronic pain. The purpose of this study was to explore the treatment expectations of parents presenting for their first visit to a multidisciplinary pediatric chronic pain clinic.

Methods

Sample: A consecutive sample of parents of children referred to the pediatric multidisciplinary pain clinic at the Stollery Children's Hospital over a four - month period were asked to complete the study questionnaire. Potential

participants were required to meet the clinic's referral criteria of chronic pain of at least 3 months duration, chronic pain as primary complaint, and chronic pain that affects activities of daily living, school attendance, sleep, quality of life or family functioning. In addition to those criteria, parents also must have been able to speak and read English.

Procedures: Ethical approval for this study was obtained from the University of Alberta Health Research Ethics Board. Operational approval and administrative support was obtained from the Stollery Children's Hospital where the Pediatric Chronic Pain Clinic was located. Parents were approached by an assistant and asked to complete the survey while waiting for their appointment in the pain clinic. Participation was voluntary. They were asked to return the survey in a sealed envelope, whether or not they had decided to participate. Participants' anonymity was protected in this way.

Measures: Informational needs and treatment expectations were assessed using individual items based on previously developed items for CAM interventions in pediatric chronic pain (36), and from the Pediatric Complex Pain Clinic One Year Evaluation tool, Alberta Children's Hospital, Calgary. The questions were constructed and reviewed by clinical experts. Parents were asked to rank the importance of informational needs about various aspects of chronic pain and various treatment options. All items were close-ended with a response scale from 1 – 4. The response options were as follows: not important, somewhat important, important, or very important. The survey also contained two open- ended questions about other information needs and other treatment wishes. In addition, demographic data about the

child was collected including pain location, pain duration and frequency, and number of health care professionals seen regarding pain.

Results

Data were coded and checked for errors. Descriptive data were obtained for all variables.

Seventeen families were approached to participate and 14 surveys were returned, reflecting an 82% response rate. Sample characteristics are presented in Table 1.

The need for information

All the parents responded to the questions about needs for further information. Table 2 shows the ranking for each of the information questions.

Chronic pain treatment options

Table 3 shows the rankings of the parents for each the various treatment options. Overall, each of the treatment options, with the exception of having other parents assisting them, was important for the majority of the parents. However, a small number of the parents did not feel that the pain treatments for chronic pain that are offered by the pain clinic were important for their child. An attempt was made to conduct some sub-analyses on ratings of importance for responses with adequate sample size (using chi-square). Respondents were grouped based on rating on importance (important, not important) and on whether or not they had had counseling or physiotherapy to determine if exposure to the treatment affected ratings of importance. However, all expected cell frequencies were below the minimum of five, making the chi-square analysis impossible to carry out.

The two open-ended questions were left blank on ten of the surveys. Four completed surveys asked for further information that was very specific to

their child's medical conditions, and in one case, a parent asked for information about the physiology of pain. When asked about other treatment options, three completed surveys included requests. One parent expressed interest in alternative therapies, one parent stated locating cause of pain, and one asked regarding future follow-up.

Discussion

This study presents a descriptive analysis of information needs and treatment expectations of parents who presented for their first visit to a multidisciplinary pediatric chronic pain clinic over a four-month period. These results demonstrated that parents desired information about several aspects of chronic pain, including the cause of chronic pain, and treatments options including medications. An overwhelming majority of parents indicated that is was important to have information about the cause of their child's pain. This is similar to Carter's (34) findings that parents are not provided with explanations about possible causes of pain.

All parents in this study felt it was very important to receive information about ways to cope with chronic pain and about the effects of pain on both mood and on the body. The need for information is a common finding in studies addressing chronic illness and disability. Claar and Scharff (35) examined parents' perceptions of pain treatments that they believed would be most likely to help their child if the pain continued. In their study, learning to cope with the pain was the treatment most frequently cited. Hummelinck and Pollock (37) found that parents of children with chronic illness wanted an explanation of their child's diagnosis, information about management including medications, and expected outcomes of treatment. They wanted this information in order to feel involved in their child's care, to

be able to answer their child's questions, and to assist them in coming to terms with the diagnosis. Similarly, Starke and Möller (38) found that parents sought information because full information was not provided at the time of diagnosis, or that they were interested in learning more about their child's condition. Fisher's review of the literature examined the needs of parents whose children are chronically ill. Parents had an overwhelming desire for more information about their child's diagnosis and treatment, and that they wanted this information to be empowered in creating partnerships with health care professionals and to reduce uncertainty (39). Jackson et al (40) found that parents reported needing information about their child's condition, symptoms, tests and treatment, but that they often found it difficult to retain information.

The majority of the children in this study had lived with chronic pain for greater than two years. During this time, the majority had seen at least two health care providers about the pain. This finding is similar to what Eccleston and Malleson (41) described as a "diagnostic vacuum" in this population as physicians who care for these children often investigate the child and refer to specialists for further evaluation searching for a cause of the pain. Children in one of their studies experienced an average pain duration of four years. (42). Dell'Api, Rennick and Rosmus (43) examined how children with chronic pain interacted with health care professionals. In their sample, the children had interacted with at least two different health care professionals, the majority being physicians, prior to being referred to a chronic pain service.

The biopsychosocial perspective of chronic pain addresses the many factors that may contribute to the pain. According to McGrath and Ruskin (44), treatments regimes for chronic pain are often comprised of the '3 P'

approach – pharmacological, psychological and physical therapy. Parents need to understand the reasons for this approach in order to follow treatment recommendations. The findings from this current study suggest that while the majority of these parents ranked the different therapies as important, a significant number did not. Education about the importance of the approach and potential treatment outcomes using this approach must be provided to parents early in the referral process in order to help parents follow through with recommended treatments.

Many of the parents in this study ranked receiving additional medical tests as important. Parents are understandably concerned that perhaps additional testing may uncover an organic explanation for the cause of the pain. Schechter (19) discussed how family physicians often continue to investigate the pain and that the family may perceive this continued investigation as evidence that a cause has yet to be uncovered. This continued investigation often leads families to request further testing, and to even search for another health care professional who may order further testing. It is important for health professionals working with children to know which red flags would indicate the need for further investigations and to reassure families that further testing would be ordered if indicated.

Parents in this study were asked to rank the importance of the delivery of various treatments and information about chronic pain. The most important aspect to all of the parents was having the pain team 'be there' for them, followed by having reading materials, attending information sessions, and of less importance was having other parents be there. This is similar to the findings of Nuutila and Salanterä (45) who found that it is important for parents to be able to contact a health professional who knows their child, to

receive information and to develop mutual trust with health care personnel. Parents have identified that having confidence in the doctors, and getting answers to questions are important influences in satisfaction with their child's care (46) Parents of children with disabilities preferred to receive information by personal communication with written communication as a backup(47).

Although these preliminary findings may be difficult to generalize beyond this clinical sample, the demographic data indicates that this sample is similar to that of Bennett, Huntsman and Lilley (10) who examined the experience of 43 children referred to a pain clinic in a similar tertiary setting. In their sample, 82% of children indicated multiple pain sites, 81% experienced pain at least 2 – 4 days of the week and 63% of the children had experienced pain for over 2 years.

An interesting observation in this study is that some very young children are experiencing chronic pain. One of the children whose parent participated was 4 years old. It is evident in the literature that younger children may have chronic pain (48, 49). However, we lack the tools to reliably measure this in infants and toddlers (50). There is a growing body of research into the long-term consequences of painful experiences in neonates as possible contributors to central sensitization. Taddio et al (51) in a seminal study found that infants who underwent circumcision without analgesia demonstrated stronger pain responses to vaccinations 4-6 months after surgery. Neonatal pain may lead to possible behavioral and personality changes in children (52).

Limitations of this study

The sample size was small and data was collected over a relatively short time of four months. The vast majority of the respondents were

mothers. This however is similar to many of the cited pediatric studies in which it is most commonly the mother who brings the child to appointments. For this study, the parent who attended that appointment was asked to complete the study. The sample may not be representative as there may be children who have chronic pain who were not referred to the multidisciplinary pain clinic, or who may have refused referral to the clinic.

Conclusions and Future Directions

This study found that parents presented to the pain clinic desiring further information about several aspects of chronic pain. It was evident from the study that the majority of parents felt that the treatment approaches of pharmacology, physiotherapy and psychosocial therapy were important, but that for some parents, these were not important treatments.

Chronic pain is multifaceted, and treatment options attempt to address multiple domains of chronic pain's impact on both the child and the family. Having an understanding of what parents do know about chronic pain, which specialists they have already seen for the pain, and what treatments they believe might assist their child will help those who work with these children to determine which treatment options the child and family are interested in. This could also help health care providers understand if parents may require more information before they are willing to investigate certain treatment options. Future studies are required on larger samples to determine the treatment expectations of parents. In addition, future studies should involve asking the children about their treatment expectations to determine if there are any differences between parent and child information needs and understanding of treatment options.

Table 1: Demographic Data

Age of the child	
Mean (SD)	12.85 yrs (3.5)
Range	4-17
Relationship to child	
Mother	12 (86%)
Father	0
Both	1 (7%)
Duration of pain	
< 3 months	0
3 – 6 months	0
6 – 12 months	2 (14%)
1 – 2 years	2 (14%)
> 2 years	10 (71%)
Frequency of pain	
Daily	11 (79%)
5-6 days/week	1 (7%)
2-4 days/week	1 (7%)
1 day/week	0
< 1day/week	0
Pain site/Diagnosis	
Headache	7
Abdominal pain	7
Muscular pain	4
Fibromyalgia	4
CRPS	5
Sickle Cell	1
Other	4

CRPS – Complex Regional Pain Disorder

Health Professionals seen about the pain	
Physician	12
Psychologist	5
Physiotherapist	3
Naturopath	3
Acupuncture	1
Chiropractor	1
Massage	1

Not all responses sum to 14 because participants could make multiple responses

Table 2: How important is it to receive information about chronic pain

Information about:	Not Important n (%)	Somewhat Important n (%)	Important n (%)	Very Important n (%)
Cause of pain	0	0	3 (21%)	10 (71%)
Treatments	0	0	0	13(93%)
Drugs to help the pain	0	3 (21%)	5 (36%)	5 (36%)
Ways to cope with the pain	0	0	0	14(100%)
Effects of pain on feelings or mood	0	0	0	14(100%)
Effects of pain on the body	0	0	0	14(100%)

Percentages do not sum to 100% due to missing values

Table 3: How important is each pain treatment

Pain Treatment:	Not Important n (%)	Somewhat Important n (%)	Important n (%)	Very Important n (%)
Receiving pain drugs	2(14%)	2(14%)	4(29%)	6(43%)
Receiving additional medical tests	1(7%)	3(21%)	3(21%)	6(43%)
Having physiotherapy	2(14%)	4(29%)	2(14%)	6(43%)
Getting counseling or psychological help	2(14%)	1(7%)	4(29%)	6(43%)
Getting reading materials about chronic pain	1(7%)	1(7%)	5(36%)	7(50%)
Being able to attend information sessions	1(7%)	4(29%)	3(21%)	6(43%)
Having the pain team be there for you	0	0	1(7%)	13(93%)
Having other parents be there for you	3(21%)	3(21%)	3(21%)	4(29%)

Percentages do not sum to 100% due to missing values

References

1. Merlijn, V. P., Hunfeld, J. A., van der Wouden, J. C., Hazebroek-Kampschreur, A. A., Passchier, J., & Koes, B. W. (2006). Factors related to the quality of life in adolescents with chronic pain. *Clinical Journal of Pain, 22*(3), 306-315.

2. Roth-Isigkeit, A., Thyen, U., Stoven, H., Schwarzenberger, J., & Schmucker, P. (2005 Feb). Pain among children and adolescents: Restrictions in daily living and triggering factors *Pediatrics, 115*(2), e152-62.

3. Perquin, C.W., Hazenbroek-Kampschreur, A., Hunfeld, J., Bohnen, A.M., van-Suijlekom-Smit, L.W., Passchier, J., & van der Wouden, J.C. (2000). Pain in children and adolescents: a common experience. *Pain, 87,* 51 – 58.

4. Eccleston, C., Bruce, E., & Carter, B. (2006). Chronic pain in children and adolescents. *Pediatric Nursing, 18*(10), 30 - 33

5. Kristjansdottir, G. (1997). Prevalence of pain combinations and overall pain: a study of headache, stomach pain and back pain among school-children. *Scandanavian Journal of Social Medicine, 25,* 58 – 63.

6. Bursch, B., Joseph, M.H., & Zeltzer, L.K. (2002). Pain –associated disability syndrome. In Schechter, N.L., Berde, C.B., & Yaster, M. *Pain in Infants, Children and Adolescents,* 2nd Ed. Lippincott, Williams & Wilkins, Philadelphia.

7. Gauntlett-Gilbert, J., & Eccleston, C., (2007). Disability in adolescents with chronic pain: patterns and predictors across different domains of functioning. *Pain, 131,* 132 - 141

8. Zeltzer, L., Bursch, B., & Walco, G. (1997). Pain responsiveness and chronic pain: a psychobiological perspective. *Developmental and Behavioral Pediatrics 18*(6), 413 – 422.

9. Konijnenberg, A. Y., Uiterwaal, C. S., Kimpen, J. L., van der Hoeven, J., Buitelaar, J. K., & de Graeff-Meeder, E. R. (2005). Children with unexplained chronic pain: Substantial impairment in everyday life. *Archives of Disease in Childhood, 90*(7), 680-686.

10. Bennett, S.M., Huntsman, E., & Lilley, C.M. (2000). Parent perceptions of the impact of chronic pain in children and adolescents. *Children's Health Care, 29,* 147-159.

11. Sällfors, C., Fasth, A., & Hallberg, L.R. (2002). Oscillating between hope and despair-a qualitative study. *Child Care, Health and Development, 28,* 495 – 505

12. Eccleston, C., Crombez, G., Scotford, A., Clinch, J., & Connell, H. (2004). Adolescent chronic pain: Patterns and predictors of emotional distress in adolescents with chronic pain and their parents. *Pain, 108*(3), 221-229.

13. Jordan, A.L., Eccleston, C., & Osborn, M. (2007) Being a parent of the adolescent with complex chronic pain: an interpretive phenomenological analysis. *European Journal of Pain, 11,* 49-56.

14. Hunfeld, J., Perquin, C., Duivenvoorder, H., Hazenbroek-Kampschreur, A., Passchier, J., van-Suijlekom-Smit, L., & van der Wouden, J., (2001). Chronic pain and its impact on quality of life in adolescents and their families. *Journal of Pediatric Psychology, 26*(3), 145-153.

15. Goubert, L., Eccleston, C., Vervoort, T., Jordan, A., & Crombez, G., (2006). Parental catastrophizing about their child's pain: the parent version of the pain catastrophizing scale (PSC-P); a preliminary validation. *Pain, 123,* 254 -263.

16. Lynch, A.M., Kashikar-Zuck, S., Goldschneider, K.R., & Jones, B. (2006). Psychosocial risks for disability in children with chronic back pain. *The Journal of Pain, 7,* 244-251

17. American Pain Society Pediatric Chronic Pain Advocacy Statement (2006). Retrieved from www.ampainsoc.org on July 20, 2007.

18. Zeltzer, L.K., Tsao, J.C., Bursch, B., & Myers, C.D. (2006). Introduction to the special issue on pain: from pain to pain-associated disability syndrome. *Journal of Pediatric Psychology, 31*(7), 661 – 666.

19. Schechter, N. L. (2006). Treatment of acute and chronic pain in the outpatient setting. In Finley, G.A., McGrath, P.J., & Chambers, C.T. *Bringing Pain Relief to Children: treatment approaches.* Totowa; Humana Press.

20. Connelly, M. & Schanberg, L. (2006). Latest developments in the assessment and management of chronic musculoskeletal pain syndromes in children. *Current Opinion in Rheumatology, 18,* 496-502.

21. Kashikar-Zuck, S. (2006). Treatment of children with unexplained chronic pain. *The Lancet, 367,* 380 – 382.

22. Malleson, P.N., Connell, H., Bennett, S.M., & Eccleston, C. (2001). Chronic musculoskeletal and other idiopathic pain syndromes. *Archives of Disease in Childhood, 84,* 189 – 192.

23. Blecourt, A., Preuper, H., Van Der Schans, C., Groothoff, J., & Reneman, M. (2008). Preliminary evaluation of a multidisciplinary pain management program for children and adolescents with chronic musculoskeletal pain. *Disability and Rehabilitation, 30,* 13 – 20.

24. Popenhagen, M. (2006). Undertreatment of pain and fears of addiction in pediatric chronic pain patients: how do we stop the problem? *Journal for Specialists in Pediatric Nursing, 11,* 61 – 67.

25. Walstrom, J., (2004). The child with chronic pain. *Journal for Specialists in Pediatric Nursing, 9,* 135 – 138.

26. Howard, R. (2003). Current status of pain management in children. *Journal of the American Medical Association, 290,* 2464-2469.

27. Matthews, E (2002). A snapshot view of the impact of chronic pain on adolescents. *British Journal of Nursing, 11,* 735 – 744.

28. Eccleston, C., Yorke, L., Morley, S., Williams, A., & Mastroyannopoulou, K., (2003). Psychological therapies for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database of Systematic Reviews, 1,* 1-33.

29. Damen, l., Bruijn, J., Koes, B., Berger, M., Passchier, J., & Verhagen, A. (2005). Prophylactic treatment of migraine in children. Part 1. A

systematic review of non-pharmacological trials. *Cephalgia, 26,* 373 – 383.

30. McGrath, P., Dick, B., & Unrah, A. (2003). Psychological and behavioral treatment of pain in children. In Schechter, N.L., Berde, C.B., & Yaster, M. *Pain in Infants, Children and Adolescents,* 2nd Ed. Lippincott, Williams & Wilkins, Philadelphia.
31. Holden, E., Deichmann, M., & Levy, J. (1999). Empirically supported treatment in pediatric psychology: recurrent pediatric headache. *Journal of Pediatric Psychology, 24,* 91 – 109.
32. Walco, G., Sterling, C., Conte, P., & Engel, R. (1999). Empirically supported treatments in pediatric psychology: disease-related pain. *Journal of Pediatric Psychology, 24,* 155 – 167.
33. Peng, P., Stinson, J., Choiniere, M., Dion, D., Intrater, H., LeFort, S., Lynch, M., Ong, M., Rashiq, S., Tkachuk, G., & Veillette, Y. (2007). Dedicated multidisciplinary pain management centers for children in Canada: the current status. *Canadian Journal of Anesthesia, 54,* 963 – 968.
34. Carter, B. (2002). Chronic pain in childhood and the medical encounter: Professional ventriloquism and hidden voices. *Qualitative Health Research, 12*(1), 28-41
35. Claar, R. L., & Scharff, L. (2007). Parent and child perceptions of chronic pain treatments. *Children's Health Care, 36*(3), 285-301.
36. Tsao, J., Meldrum, M., Bursch, B., Jacob, M., Su, C., & Zeltzer, L. (2005). Treatment expectations for CAM interventions in pediatric chronic pain patients and their parents. *eCAM, 4,* 521-527.

37. Hummelinck, A. & Pollock, K. (2006). Parents' information needs about the treatment of their chronically ill child: a qualitative study. *Patient Education and Counseling, 62,* 228 – 234.

38. Starke, M. & Möller, A. (2002). Parents' needs for knowledge concerning the medical diagnosis of their children. *Journal of Child Health Care, 6,* 245-257.

39. Fisher, H.R. (2001). The needs of parents with chronically sick children" a literature review. *Journal of Advanced Nursing, 36,* 600 – 607.

40. Jackson, R., Baird, W., Davis-Reynolds, L., Smith, C., Blackburn, S., & Allsebrook, J. (2007). Qualitative analysis of parents' information needs and psychosocial experiences when supporting children with health care needs. *Health Information and Libraries Journal, 25,* 31 – 37.

41. Eccleston, C. & Malleson, P. (2003). Managing chronic pain in children and adolescents. *British Medical Journal, 326,* 1408 – 1409.

42. Eccleston, C., Mallseon, P., Clinch, J., Connell, H., & Sourbut, C. (2003). Chronic pain in adolescents: an evaluation of a program of interdisciplinary cognitive behavior therapy. *Archives Disease of the Child, 88,* 881 – 885.

43. Dell'Api, M., Rennick, J. & Rosmus, C. (2007). Childhood chronic pain and health care professional interactions: shaping the chronic pain experiences of children. *Journal of Child Health Care, 11,* 269 – 286.

44. McGrath, P. & Ruskin, D (2007). Caring for children with chronic pain: ethical considerations. *Pediatric Anesthesia, 17,* 505 – 508.

45. Nuutila, L. & Salanterä, S. (2006). Children with long-term illness: parents' experiences of care. *Journal of Pediatric Nursing, 21,* 153 – 160.

46. Ammentorp, J., Mainz, J. & Sabroe, S. (2006). Determinants of priorities and satisfaction in pediatric care. *Pediatric Nursing, 32,* 333 – 340, 348.

47. Pain, H. (1999). Coping with a child with disabilities from the parents' perspective: the function of information. *Child Care, Health and Development, 25,* 299 – 312.

48. Rossi, L., Vajani, S., Cortinovis, I., Spreafico, F., & Menegazzo, L. (2008). Analysis of the international classification of headache disorders for diagnosis of migraine and tension-type headache in children. *Developmental Medicine and Child Neurology, 50,* 305 – 310.

49. Kulas, D., & Schanberg, L. (2003). Musculoskeletal pain in children. In Schechter, N.L., Berde, C.B., & Yaster, M. *Pain in Infants, Children and Adolescents,* 2nd Ed. Lippincott, Williams & Wilkins, Philadelphia

50. Johnston, C., Stevens, B., Boyer, K., & Lang Porter, F (2003). Development of psychological responses to pain and assessment of pain in infants and toddlers. In Schechter, N.L., Berde, C.B., & Yaster, M. *Pain in Infants, Children and Adolescents,* 2nd Ed. Lippincott, Williams & Wilkins, Philadelphia

51. Taddio, A., Katz, J., Ilersich, A., & Koren, G. (1997). Effect of neonatal circumcision on pain response during subsequent routine vaccination. *Lancet, 349,* 599 – 603.

52. Goldschneider K., & Anand, K. (2003). Long-term consequences of pain in neonates. In Schechter, N.L., Berde, C.B., & Yaster, M. *Pain in Infants, Children and Adolescents,* 2nd Ed. Lippincott, Williams & Wilkins, Philadelphia

General Discussion

A pilot study serves several purposes. It provides an opportunity to test the research techniques including the data collection tools. It also furnishes researchers with information about sampling and response rates. As a pilot study, this thesis has offered many insights about ways to conduct the larger study. It has also given me some important knowledge about doing research.

Research Tool

No tool was found in the literature that asked parents specifically about their treatment expectations prior to treatment. The tool developed for use in this study was adapted from questionnaires used in the Complex Pain Clinic at the Alberta Children's Hospital, and the UCLA Pediatric Pain Research program (Tsao, 2003). I was fortunate to be able to consult with both of these organizations when adapting their questions for this study, and learn from their research and expertise.

The survey tool used in this study could be modified and improved. One change that could enhance item response rate is to format the survey differently. Rather than printing on both sides, it could be printed only on one side or as a booklet so that respondents do not miss items. Another possible change is to include *don't know* as a response option. The responses were forced choices but perhaps *don't know* is a valid option. Third, answers to the question regarding number of health professionals consulted indicated some confusion. Some parents included the number, others put a check mark on the line, and others left it blank. When revising this question, it would be best to clarify what information parents were to provide. A *don't know* option would

have been useful for parents who did not remember how many professionals, or which professionals they had seen.

Sample

The sample size in a pilot study is typically small and data are collected over a relatively short time. I learned the importance of an adequate sample size, not simply the overall sample size, but also the size of sub-groups that could be important for analyses. When an attempt was made to study the relationship between which health care professionals had been consulted and importance of the different therapies (such as physiotherapy and psychology), the sample sizes were too small, even for nonparametric statistics. A larger sample size would allow for statistical analysis. In order to obtain a larger sample data would need to be collected over a longer time, or would need to be collected from more than one pediatric clinic. Data could also be collected from other pediatric clinics that see children with specific chronic pain conditions, such as neurology (headaches), rheumatology, and gastro-intestinal (recurrent abdominal pain). This might increase the sample sizes to allow analysis related to pain location and importance of different therapies.

Study Design

This study utilized a descriptive cross-sectional design. The descriptive approach would still be appropriate for a larger study, as little is known about parent expectations for chronic pain treatment expectations. The descriptive study design provides detailed information about variables, but does not examine causal relationships between variables. In descriptive studies, literature exists about the variables but the variables may not have

been studied in a particular population (Brink & Wood, 2001). Cross-sectional designs involve the collection of data at one point in time.

I am the Nurse Practitioner in the clinic and met directly with each of the families during the study. Parents were recruited for the study by the clinic's administrative staff prior to their first appointment. A letter outlining the study was provided for all parents and consent was implied by completing the study. I did not directly recruit parents but was actively involved in their child's care. Ethically, we did take steps to make certain that potential participants did not feel coerced to participate. This included offering them opportunities to decline refusing to take the survey, or by placing the uncompleted survey into the envelope and returning it to the clinic staff. However, one parent returned the uncompleted survey directly to me on his own volition and discussed his reasons for refusal with me. This required me to reassure this parent that his refusal would not affect his child's care, or our professional relationship. Role conflict when the nurse is the researcher is always possible. Colbourne and Sque (2004) discussed the potential conflict of the dual roles of nurse and nurse researcher. Nurses as researchers are committed to advancing knowledge but should not 'divorce' themselves from providing care. I learned that the consent process that met the Health Research Ethics Board's requirements still might produce conflict for parents who may feel that care of their child could be affected by their choice to participate. I did feel that the majority of parents participated willingly in the study. The literature supports that parents report high satisfaction with a consent process that involves explanation of the study and an easy to read information sheet. (Franck, Winter, & Oulton, 2007). The information sheet in this study was at a Fleish-Kincade Grade 6 reading level.

Contributions and Future Directions

Contributions

The biopsychosocial approach to chronic pain management involves many different treatment strategies aimed at improving the quality of life without necessarily "curing" the pain. It is essential to understand parents' views on the nature of their child's pain and what they feel may best help their child. This pilot study suggests the following:

1. Parents do not always know the cause of their child's pain and want this addressed.
2. Parents want more information about several aspects of chronic pain, including the effects of pain on mind and body, coping strategies, and treatments including medications.
3. Although the majority of parents see the different pain treatments as important, a small number in this sample did not feel that the different treatment approaches were important.
4. It is significant that one of the children whose parent completed the study was four years of age. There is little research into chronic pain in children under the age of seven although epidemiological studies demonstrate that younger children do experience chronic pain (Perquin et al, 2000).

It is important for our pediatric chronic pain clinic to ask parents about their understanding of chronic pain and any treatment expectations at or prior to the first clinic visit. Chronic pain is multifaceted, and treatment options address multiple domains of both the child and the family. Having an understanding of what parents do know about chronic pain, which specialists

they have already seen for the pain, and what treatments they believe might assist their child will help us work with these parents to determine which treatment options they are interested in. This could also help health care providers understand if parents require more information before they are willing to investigate certain treatment options. This research is very important for our clinic as we develop treatment programs to manage chronic pain in children, many of whom have complex medical problems. The clinic in which this study was completed opened when the study commenced. Learning more about treatment expectations and how best to meet them is important in securing resources to meet the needs of the families seen in this clinic.

Nursing Implications

Nurses are vital members of pediatric chronic pain clinics as they coordinate many aspects of treatment and are often the primary contact for the family. These nurses are well positioned to answer questions and address the needs of the child and family. (Peng, et al, 2007; Berde & Solodiuk, 2003). Most of the nursing roles in the Canadian pediatric chronic pain clinics are advanced practice roles, either Nurse Practitioners or Clinical Nurse Specialists (Reid, unpublished). Advanced practice nurses are involved in all aspects of pain management including providing therapy, prescribing medications and developing treatment plans (CARNA, 2005; Lewandowski, 2004; Walstrom 2004: CNA, 2003). Advanced practice nurses are involved in research projects across Canada including improving pain education (Watt-Watson et al, 2008). It is within the domains of advanced practice nurses to facilitate research and to disseminate research findings. (CARNA, 2005; CNA, 2003). Completing this research was important for me

in developing my role as an advanced practice nurse. The findings of this study have assisted me in working with the children and families in the clinic. I have incorporated these findings into my initial assessment documentation by asking parents about their previous encounters with health care professionals, their understanding of their child's pain, their treatment expectations, and their willingness to address different treatment modalities. This research has also demonstrated the need to provide written materials about chronic pain in children for the parents. As a result of this study, I am building a library of reading materials to loan out to families.

Health Care Implications

Having chronic pain is expensive. Sleed, Eccleston, Beecham et al (2005) examined the economic impact of adolescent chronic pain and determined the mean cost was approximately £8000 ($16000) Canadian per year per child. These costs include health services costs and out-of-pocket expenses to families. Treatment options for chronic pain such as community-based psychological services, physiotherapy, or certain medications may not be covered. Discussing treatment options and addressing treatment expectations is important from an economic view as well. Pediatric pain clinics in Canada are fortunate to have multidisciplinary teams but few clinics exist (Peng et al, 2007). The majority of children who suffer from debilitating chronic pain unfortunately will not have access to a clinic. An important task for these teams then is to develop resources and disseminate information about chronic pain to primary care providers who see these children and their families. It was evident from the study and from the literature review that many children experienced daily pain for longer than two years, and that their parents need information about the causes of pain and how to manage it.

Future Directions

This study asked the parents about their treatment expectations. Future studies with larger sample sizes are required to determine the treatment expectations of parents. Larger sample sizes would require collaboration with other dedicated pediatric chronic pain clinics or longer recruitment periods. Future studies should also ask the children about their treatment expectations in a developmentally appropriate manner. Longitudinal research into treatment expectations and treatment outcomes in pediatric chronic pain patients is necessary to determine if pretreatment expectations influence treatment outcomes. Future research should look at innovative ways to provide parents and health care providers with information about chronic pain, such as use of the Internet, and use of technologies such as video conferencing. Studies should be designed from an integrative approach such as the one proposed by Palermo and Chambers (2005) as pediatric chronic pain is complex and should be examined from a family perspective.

References

Brink, P.J. & Wood, M.J. (2001). *Basic Steps in Planning Nursing research: from question to proposal.* 5th Ed. Sudbury MA.; Jones & Bartlett Publishers.

Canadian Nurses Association (2003). The Nurse Practitioner: position statement. Retrieved August 27, 2008. http://www.cna-aiic.ca/CNA/documents/pdf/publications/PS68_Nurse_Practitioner_June_2003_e.pdf

Colbourne, L. & Sque, M. (2004). Split personalities: role conflict between the nurse and the nurse researcher. *NT Research, 9,* 297 – 304.

College and Association of Registered Nurses of Alberta (2005). Nurse Practitioner competencies. Retrieved August 27, 2008. http://www.nurses.ab.ca/Carna-Admin/Uploads/NP%20Competencies.pdf.

Franck, L., Winter, I., & Oulton, K. (2007). The quality of parental consent for research with children: a prospective repeated measure self-report survey. *International Journal of Nursing Studies, 44,* 525 – 533.

Lewandowski, W. (2004). Psychological factors in chronic pain: a worthwhile undertaking for nursing? *Archives of Psychiatric Nursing, 18,* 97 – 105.

Palermo, T.M., & Chamber, C, T. (2005). Parent and family factors in pediatric chronic pain and disability: an integrative approach. *Pain, 119,* 1 – 4.

Peng, P., Stinson, J., Choiniere, M., Dion, D., Intrater, H., LeFort, S., Lynch, M., Ong, M., Rashiq, S., Tkachuk, G., & Veillette, Y. (2007). Dedicated multidisciplinary pain management centers for children in

Canada: the current status. *Canadian Journal of Anesthesia, 54,* 963 – 968.

Perquin, C.W., Hazenbroek-Kampschreur, A., Hunfeld, J., Bohnen, A.M., van-Suijlekom-Smit, L.W., Passchier, J., & van der Wouden, J.C. (2000). Pain in children and adolescents: a common experience. *Pain, 87,* 51 – 58.

Sleed, M., Eccleston, C., Beecham, J., Knapp, M., & Jordan, A. (2005). The economic impact of chronic pain in adolescence: methodological considerations and a preliminary cost-of-illness study. *Pain, 119,* 183 – 190.

Stommel, M., & Wills, C.E. (2004). *Clinical research: concepts and principles for advanced practice nurses.* Philadelphia; Lippincott Williams & Wilkins.

Stollery Children's Hospital. (2007, September). *Pediatric chronic pain services: model development.* Edmonton, AB; Reid, K.

Walstrom, J., (2004). The child with chronic pain. *Journal for Specialists in Pediatric Nursing, 9,* 135 – 138.

Watt-Watson, J., Musclow, S., Davis, D., McGillion, M., Stinson, J., Madden, S., Reid, K. (2008). National Projects Strategy Initiative. Canadian Pain Society. Poster session presented at the annual conference of the Canadian Pain Society, Victoria BC.

Appendix 1: Treatment Expectations of Parents Whose Children are Referred to a Pediatric Chronic Pain Clinic

Review of the Literature

Background

Chronic pain in childhood is increasingly being recognized as a significant clinical problem that affects multiple domains of the lives of both the child and the family. Epidemiological studies have shown that chronic pain in childhood affects between 15 – 39% of children (Merlijn, Hunfeld, van der Wouden, Hazebroek-Kampschreur, Passchier, & Koes, 2006; Roth-Isigkeit, Thyen., Stoven, Schwarzenberger, & Schmucker, 2005; Perquin, Hazenbroek-Kampschreur, Hunfeld, Bohnen, van-Suijlekom-Smit, Passchier, & van der Wouden, 2000). Headache is the most common chronic pain complaint expressed by children, followed by abdominal pain and musculoskeletal pain
(Eccleston, Bruce, & Carter, 2006). Up to 50% of children who report chronic pain indicate multiple sites, most commonly headache and abdominal pain (Kristjansdottir, 1997). For most children, chronic pain is not debilitating in the long term. However, for a small percentage of children, the pain can be severe and disabling, leading to the development of "pain associated disability syndrome", a syndrome characterized by severe difficulties with functional abilities regardless of the location or cause of the pain (Bursch, Joseph, & Zeltzer, 2003). Affecting between 1 – 3% of the general pediatric population these are the children who are most likely to be referred to a pediatric multidisciplinary pain clinic (Eccleston et al, 2006).

Chronic Pain in Context

Pain is defined by the International Association for the Study of Pain as "an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage" (IASP, 2007). Acute pain, or nociceptive pain associated with an injury or infection is often intense, but subsides and usually disappears as the tissues heal. Acute pain is often protective, in that it may protect from further injury to the tissues. It serves a biological purpose, allowing the injured tissue time to heal (Berde, Lebel, & Olsson, 2003). Acute pain is often described as visible, as the injury or illness can usually be seen and assessed. Chronic pain, or neuropathic pain, differs from acute pain in many ways. It may arise after an injury or infection, but the pain continues after the tissues have healed. It may also occur in the absence of known tissue injury. Chronic pain is often described as invisible. It can occur due to an abnormal enhanced state involving sensitization of the central nervous system (Vanderah, 2007). It is now recognized that chronic pain is subjective, multidimensional, and involves physical, psychological and behavioral aspects and serves no useful biological purpose (Gatchel, Peng, Peters, Fuchs, & Turk, 2007; Breen, 2002). In children, chronic pain is "the result of a dynamic integration of biological processes, psychological factors, and sociocultural context, considered within a developmental trajectory "(American Pain Society, 2000 p1). For the purpose of this thesis McGrath's definition of chronic pain as "any prolonged pain that lasts a minimum of three months, or any pain that recurs throughout a minimum period of three months" (McGrath,1999, p8`) will be utilized.

Living with chronic pain – the child's perspective

Chronic pain affects several domains of the child's life, regardless of the underlying cause of the pain. Children and adolescents may experience decreased confidence in their ability to function, increased physical vulnerability to pain, increased somatic symptoms, decreased functioning, depression, and anxiety (Gauntlett-Gilbert, & Eccleston, 2007; Zeltzer, Bursch, & Walco, 1997). Children and adolescents with unexplained chronic pain often report impairment in sports activities, school absences, limitations in social functioning, and sleep disturbances including nocturnal wakening (Konijnenberg, Uiterwaal, Kimpen, van der Hoeven, Buitelaar, & de Graeff-Meeder, 2005; Bennett, Huntsman, & Lilley, 2000). Children and adolescents also often report that pain controls their lives and prevents them from living a normal life (Sällfors, Fasth, & Hallberg, 2002).

Parenting the child with chronic pain

Parents of children with chronic pain also suffer. For instance they report high levels of depression, anxiety and parenting distress (Jordan, Eccleston, & Osborn, 2007; Eccleston, Crombez, Scotford, Clinch, & Connell, 2004) and restrictions in their own social activities (Hunfeld, Perquin, Duivenvoorder, Hazenbroek-Kampschreur, Passchier, van-Suijlekom-Smit, & van der Wouden, 2001). Parents of children with chronic pain may face challenges adjusting to acceptance of pain due to pain catastrophizing, which is thinking that pain is a sign of impending health catastrophe. Parental catastrophic thinking about pain contributes to pain associated disability in the child with chronic pain (Goubert, Eccleston, Vervoort, Jordan, & Crombez, 2006; Lynch, Kashikar-Zuck, Goldschneider, & Jones, 2006).

Managing chronic pain in children: the biopsychosocial approach

As chronic pain has an impact on many dimensions of the lives of both the child and family, a multidimensional approach to treatment is required. The biopsychosocial approach to chronic pain management attempts to address the many dimensions involved. This approach addresses the biological basis of pain, the psychological interventions that assist the child and family to understand and cope with pain and its consequences, and alter unhelpful responses to pain, and the social factors affected by the pain, such as school and other activities (Schechter, 2006; Zeltzer, Tsao, Bursch, & Myers, 2006; American Pain Society 2000). A multidisciplinary approach involving pharmacological management, physical therapy and psychological intervention to assist the child and family to manage the pain and reverse the disability improves functioning and the child's wellbeing (Connelly, & Schanberg, 2006; Kashikar-Zuck, 2006; Malleson, Connell, Bennett, & Eccleston, 2001).

Pharmacological management of chronic pain in children

There are few studies examining pharmacological chronic pain management in children. Much of the literature in this area is extrapolated from adult studies, or is based on case studies (Charlton, 2005). There is evidence that pharmacological management of symptoms such as anxiety and sleep deprivation can improve quality of life in children with chronic pain (Bursch, et al, 2003). Tricyclic antidepressants and anticonvulsants are often prescribed for children suffering from neuropathic pain syndromes however, careful monitoring and titration of these medications is recommended due to the limited safety and efficacy data (Berde, et al, 2003). Parents are often reluctant to administer medications to their children based on several factors, including fear of adverse reactions and fear of addiction

(McLaren & Kain, 2008; Lazaratou, Anagnostopoulos, Alevizos, Havaiara, & Ploumpidis, 2007; Forward, Brown & McGrath, 1996). These factors must be addressed with parents prior to initiating pharmacological management as the literature is lacking. However, it is important for clinicians working with these children to utilize adequate analgesics to manage pain (Currie, 2006).

Physical therapy and chronic pain

Exercise including aerobic conditioning has been shown to improve mood, quality of sleep, and activate endogenous pain-inhibiting systems. (Eccleston and Eccleston, 2004; McCarthy, Shea & Sullivan, 2003)

Psychological interventions and chronic pain

There is good evidence that psychological treatments, including relaxation and cognitive- behavioral therapy are effective for certain chronic pain conditions in children. (Eccleston, Yorke, Morley, Williams, & Mastroyannopoulou, 2003). Relaxation alone or in combination with biofeedback, or cognitive-behavioral therapy has been shown to be effective in pediatric headache (Damen, Bruijn, Koes, Berger, Passchier & Verhagen, 2005; Holden, Deichmann, & Levy, 1999). Cognitive behavioral therapies are often utilized in disease-related pain including arthritis and cancer (McGrath, Dick & Unruh, 2003; Walco, Sterling, Conte, & Engel, 1999). Families of children with recurrent abdominal pain who participated in cognitive behavioral family therapy reported less abdominal pain and fewer school absences (Robins, Smith, Glutting, & Bishop, 2005).

The biopsychosocial approach to managing chronic pain is effective if the parents and child agree that this approach is more helpful than continuing to search for a cure (Lindley, Glaser, & Milla, 2005; Crushell, Rowland, Doherty, Gormally, Harty, Bourke& Drumm, 2003). This approach is better

suited to understanding how chronic pain pathways develop than the biomedical approach utilized by many care providers. The biomedical approach to chronic pain often leads to more referrals and more unnecessary tests (Zeltzer, Tsao, Bursch & Myers, 2005).

Managing pediatric chronic pain in multidisciplinary pediatric pain clinics

Dedicated pediatric chronic pain clinics have been developed throughout the world to assist children and their families in managing disabling chronic pain however few clinics are available in Canada. Peng et al (2007) examined the five available dedicated pediatric pain clinics in Canada. The clinics all provide cognitive-behavioral therapy including relaxation, imagery and individual sessions. Staff includes physicians, nurses, psychologists, and physiotherapists. The majority of the clinics only have one clinic day per week. Median weight time to first appointment was four weeks but for one clinic, the wait time was as long as nine months. Median number of new referrals seen per year was 31, with a range of 30 – 86. All clinics are located in urban areas in only five of the provinces. Since this study was published two more pediatric chronic pain clinics have opened in Canada (Reid, 2007, unpublished data).Given the epidemiological data on the prevalence of chronic pain and the limited time available in clinics to manage these children, few children would be fortunate enough to have access to these clinics.

The multidisciplinary pediatric chronic pain team approach has been shown to improve the quality of life of children with chronic pain (Blecourt, Preuper, Van Der Schans, Groothoff, & Reneman, 2008; Popenhagen, 2006; Walstrom, 2004; Howard, 2003; Matthews, 2002).

What do parents expect from the multidisciplinary pain clinic?

Few studies have addressed the treatment expectations of parents and children with chronic pain. By the time a child and family are seen in a multidisciplinary pain clinic, they have often seen many specialists and are suffering from 'referral fatigue'. For some parents, a firm diagnosis has not been provided and they are still searching for a reason for their child's pain (Carter, 2002). When asked prior to attending a pain clinic what they thought would be the most helpful outcome, parents cited learning to cope with the pain and learning to manage stress. However, a significant number of parents reported that they did not know what to do for the pain, and that current therapies for pain were not effective for their child (Claar, & Scharff, 2007). Research into treatment expectations for complementary therapies in managing chronic pain in children has shown that parents rated complementary approaches as more likely to be helpful than their children did, but that the expected benefits from both complementary and conventional treatments was low for both parents and children. (Tsao, Meldrum, Bursch, Jacob, Su, & Zeltzer, 2005).

What do adult chronic pain patients expect from the multidisciplinary pain clinic?

Although little is known about treatment expectations for pediatric chronic pain, this issue has been studied in the adult chronic pain population. Studies examining the expectations of adults who attend pain clinics have found that patients want explanations of the cause of their pain, further investigations and tests, pain relief, and to be believed that their pain is real (Petrie, Frampton, Large, Moss-Morris, Johnson, & Meechan, 2005; Verbeek, Sengers, Riemens, & Haafkens, 2004; Davies, Glynn, & Kadry,

2003). It is unknown if parents of children with chronic pain have similar expectations. It is important to study these questions in pediatric populations as pain approaches, which have been validated in adult populations, lack the necessary developmental and family focus, and may in fact be potentially harmful to children and their families (American Pain Society, 2000). One example of potential harm is the pharmacological management of chronic pain. Research into the pharmacodynamics of long term pain medication use in children is lacking. The Canadian Pediatric Society (2003) recognizes that pediatric drug investigation studies are required to address growth and developmental factors, learning functions of children, and future reproductive capacity of children. The Canadian Pediatric Society (2004) also recognizes that children and their families should be involved in decision-making and that the capacity to make decisions must be developmentally appropriate for the child.

Summary

Chronic pain in childhood is common, and severe debilitating chronic pain affects many aspects of the lives of both the child and the family. The biopsychosocial approach to pediatric chronic pain is effective if parents and children understand it, and agree to address the multiple domains involved in chronic pain. Children and families seen in pediatric chronic pain clinics are often frustrated from dealing with the pain and disability, and with a health care system, which, while searching for a cause, has often not addressed the management of the pain. By the time they are referred to a pain clinic, they may have many misconceptions about the pain and do not know what to do to manage the pain and disability. More research into the treatment

expectations of parents whose children have chronic pain is necessary in order to effectively work with the child and family to manage their pain.

References

American Pain Society Pediatric Chronic Pain Advocacy Statement (2000). Retrieved from www.ampainsoc.org on July 20, 2007.

Bennett, S.M., Huntsman, E., & Lilley, C.M. (2000) Parent perceptions of the impact of chronic pain in children and adolescents. *Children's Health Care, 29,* 147-159.

Berde, C.B., Lebel, A.A. & Olsson, G. (2003) Neuropathic pain in children. In Schechter, N.L., Berde, C.B., & Yaster, M. *Pain in Infants, Children and Adolescents,* 2nd Ed. Lippincott, Williams & Wilkins, Philadelphia

Blecourt, A., Preuper, H., Van Der Schans, C., Groothoff, J., & Reneman, M. (2008). Preliminary evaluation of a multidisciplinary pain management program for children and adolescents with chronic musculoskeletal pain. *Disability and Rehabilitation, 30,* 13 – 20.

Breen, J. (2002). Transitions in the concept of chronic pain. *Advances in Nursing Science, 24,* 48 – 59.

Bursch, B., Joseph, M.H., & Zeltzer, L.K. (2003) Pain –associated disability syndrome. In Schechter, N.L., Berde, C.B., & Yaster, M. *Pain in Infants, Children and Adolescents,* 2nd Ed. Lippincott, Williams & Wilkins, Philadelphia

Bursch, B., Joseph, M.H., & Zeltzer, L.K. C., Bruce, E., & Carter, B. (2006). Chronic pain in children and adolescents. *Pediatric Nursing, 18*(10), 30 – 33

Canadian Pediatric Society (2003). Drug investigation for Canadian children: the role of the Canadian Pediatric Society. *Paediatric Child Health, 8,* 231 – 234.

Canadian Pediatric Society (2004). Treatment decisions regarding infants, children and adolescents. *Paediatric Child Health, 9,* 99 – 103.

Carter, B. (2002). Chronic pain in childhood and the medical encounter: Professional ventriloquism and hidden voices. *Qualitative Health Research, 12*(1), 28-41.

Charlton, J., Editor (2005). Pain in infants, children and adolescents. *Core Curriculum for Professional Education in Pain.* Seattle; IASP Press

Claar, R. L., & Scharff, L. (2007). Parent and child perceptions of chronic pain treatments. *Children's Health Care, 36*(3), 285-301.

Connelly, M. & Schanberg, L. (2006). Latest developments in the assessment and management of chronic musculoskeletal pain syndromes in children. *Current Opinion in Rheumatology, 18,* 496-502.

Crushell, E., Rowland, M., Doherty, M., Gormally, S., Harty, S., Bourke, B., & Drumm, B., (2003). Importance of parental conceptual model of illness in severe recurrent chronic pain. *Pediatrics, 112*(6), 1368 – 1372.

Currie, J. (2006). Management of chronic pain in children. *Archives of Disease in Childhood – Education and Practice, 91,* 111 – 114.

Damen, l., Bruijn, J., Koes, B., Berger, M., Passchier, J., & Verhagen, A. (2005). Prophylactic treatment of migraine in children. Part 1. A systematic review of non-pharmacological trials. *Cephalgia, 26,* 373 – 383.

Davies, P., Glynn, C., & Kadry, M. (2003) Expectations of patients attending a combined headache clinic. *Journal of Headache Pain, 4,* 79-82.

Eccleston, C., Crombez, G., Scotford, A., Clinch, J., & Connell, H. (2004). Adolescent chronic pain: Patterns and predictors of emotional distress

in adolescents with chronic pain and their parents. *Pain, 108*(3), 221-229.

Eccleston, C., Yorke, L., Morley, S., Williams, A., & Mastroyannopoulou, K., (2003). Psychological therapies for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database of Systematic Reviews, 1,* 1-33.

Eccleston, Z. & Eccleston, C. (2004). Interdisciplinary management of adolescent chronic pain: developing the role of physiotherapy. *Physiotherapy, 90,* 77 – 81.

Forward, S., Brown, T., & McGrath, P. (1996). Mothers' attitudes and behavior toward medicating children's pain. *Pain, 67,* 469 – 474.

Gatchel, R.J. & Peng, Y.B., Peters, M.L., Fuchs, P.N., & Turk, D.C. (2007). The biopsychosocial approach to chronic pain: scientific advances and future directions. *Psychological Bulletin, 133,* 581-624.

Gauntlett-Gilbert, J., & Eccleston, C., (2007). Disability in adolescents with chronic pain: patterns and predictors across different domains of functioning. *Pain, 131,* 132 – 141

Goubert, L., Eccleston, C., Vervoort, T., Jordan, A., & Crombez, G. (2006). Parental catastrophizing about their child's pain: the parent version of the pain catastrophizing scale (PSC-P); a preliminary validation. *Pain, 123,* 254 -263.

Holden, E., Deichmann, M., & Levy, J. (1999). Empirically supported treatment in pediatric psychology: recurrent pediatric headache. *Journal of Pediatric Psychology, 24,* 91 – 109.

Howard, R. (2003). Current status of pain management in children. *Journal of the American Medical Association, 290,* 2464-2469.

Hunfeld, J., Perquin, C., Duivenvoorder, H., Hazenbroek-Kampschreur, A., Passchier, J., van-Suijlekom-Smit, L., & van der Wouden, J., (2001). Chronic pain and its impact on quality of life in adolescents and their families. *Journal of Pediatric Psychology, 26*(3), 145-153.

IASP Pain Terminology (2007). Retrieved from http://www.iasp-pain.org/AM/Template.cfm?Section=Home&template=/CM/HTMLDisplay.cfm&ContentID=6648#Pain. July 12, 2008.

Jordan, A.L., Eccleston, C., & Osborn, M. (2007) Being a parent of the adolescent with complex chronic pain: an interpretive phenomenological analysis. *European Journal of Pain, 11,* 49-56.

Kashikar-Zuck, S. (2006) Treatment of children with unexplained chronic pain. *The Lancet, 367,* 380 – 382.

Konijnenberg, A. Y., Uiterwaal, C. S., Kimpen, J. L., van der Hoeven, J., Buitelaar, J. K., & de Graeff-Meeder, E. R. (2005). Children with unexplained chronic pain: Substantial impairment in everyday life. *Archives of Disease in Childhood, 90*(7), 680-686.

Kristjansdottir, G. (1997). Prevalence of pain combinations and overall pain: a study of headache, stomach pain and back pain among school-children. *Scandanavian Journal of Social Medicine, 25,* 58 – 63.

Lazaratou, H., Anagnostopoulos, D., Alevizos, E., Haviara, F., & Ploumpidis, D. (2007). Parental attitudes *and* opinions on the use of psychotropic medication in mental disorders of childhood. *Annals of General Psychiatry.* Downloaded from www.annals-general-psychiatry.com August 25, 2008

Lindley, K. J., Glaser, D., & Milla, P. J. (2005). Consumerism in healthcare can be detrimental to child health: Lessons from children with

functional abdominal pain. *Archives of Disease in Childhood, 90*(4), 335-337.

Lynch, A.M., Kashikar-Zuck, S., Goldschneider, K.R., & Jones, B. (2006). Psychosocial risks for disability in children with chronic back pain. *The Journal of Pain, 7,* 244-251

Malleson, P.N., Connell, H., Bennett, S.M., & Eccleston, C. (2001) Chronic musculoskeletal and other idiopathic pain syndromes. *Archives of Disease in Childhood, 84,* 189 – 192.

Matthews, E (2002). A snapshot view of the impact of chronic pain on adolescents. *British Journal of Nursing, 11,* 735 – 744.

McCarthy, C., Shea, A., & Sullivan, P. (2003). Physical therapy management of pain in children. In Schechter, N.L., Berde, C.B., & Yaster, M. *Pain in Infants, Children and Adolescents,* 2nd Ed. Lippincott, Williams & Wilkins, Philadelphia

McGrath, P. A. (1999). Chronic pain in children. In I. K. Crombie, & Croft, Peter R., Linton, Steven J., Leresche, L., & Von Korff, (Eds.), *Epidemiology of Pain*. Seattle: IASP press.

McGrath, P., Dick, B., & Unrah, A. (2003). Psychological and behavioral treatment of pain in children. In Schechter, N.L., Berde, C.B., & Yaster, M. *Pain in Infants, Children and Adolescents,* 2nd Ed. Lippincott, Williams & Wilkins, Philadelphia.

McLaren, J. & Kain, Z. (2008). Research to practice in pediatric pain: what are we missing? *Pediatrics, 122,* 443 – 444.

Merlijn, V. P., Hunfeld, J. A., van der Wouden, J. C., Hazebroek-Kampschreur, A. A., Passchier, J., & Koes, B. W. (2006). Factors

related to the quality of life in adolescents with chronic pain. *Clinical Journal of Pain, 22*(3), 306-315.

Peng, P., Stinson, J., Choiniere, M., Dion, D., Intrater, H., LeFort, S., Lynch, M., Ong, M., Rashiq, S., Tkachuk, G., & Veillette, Y. (2007). Dedicated multidisciplinary pain management centers for children in Canada: the current status. *Canadian Journal of Anesthesia, 54,* 963 – 968.

Perquin, C.W., Hazenbroek-Kampschreur, A., Hunfeld, J., Bohnen, A.M., van-Suijlekom-Smit, L.W., Passchier, J., & van der Wouden, J.C. (2000). Pain in children and adolescents: a common experience. *Pain, 87,* 51 – 58.

Petrie, K., Frampton, T., Large, R.G., Moss-Morris, R., Johnson, M., & Meechan, G. (2005). What do patients expect from their first visit to a pain clinic? *Clinical Journal of Pain, 21*(4), 297 – 301.

Popenhagen, M. (2006). Undertreatment of pain and fears of addiction in pediatric chronic pain patients: how do we stop the problem? *Journal for Specialists in Pediatric Nursing, 11,* 61 – 67.

Robins, P., Smith, S., Glutting, J., & Bishop, C. (2005). A randomized controlled trial of a cognitive-behavioral family intervention for pediatric recurrent abdominal pain. *Journal of Pediatric Psychology, 30,*397 – 408.

Roth-Isigkeit, A., Thyen, U., Stoven, H., Schwarzenberger, J., & Schmucker, P. (2005 Feb). Pain among children and adolescents: Restrictions in daily living and triggering factors *Pediatrics, 115*(2), e152-62.

Sällfors, C., Fasth, A., & Hallberg, L.R. (2002). Oscillating between hope and despair-a qualitative study. *Child Care, Health and Development, 28,* 495 – 505

Schechter, N. L. (2006). Treatment of acute and chronic pain in the outpatient setting. In Finley, G.A., McGrath, P.J., & Chambers, C.T. *Bringing Pain Relief to Children: treatment approaches.* Totowa; Humana Press.

Tsao, J., Meldrum, M., Bursch, B., Jacob, M., Su, C., & Zeltzer, L. (2005) Treatment expectations for CAM interventions in pediatric chronic pain patients and their parents. *eCAM, 4,* 521-527.

Vanderah, T.W. (2007). Pathophysiology of pain. *Medical Clinics of North America 91;* 1 – 12

Verbeek, J., Sengers, M., Riemens, L., & Haafkens, J. (2004) Patient expectations of treatment for back pain: a systematic review of qualitative and quantitative studies. *Spine, 29,* 2309-2318

Walco, G., Sterling, C., Conte, P., & Engel, R. (1999). Empirically supported treatments in pediatric psychology: disease-related pain. *Journal of Pediatric Psychology, 24,* 155 – 167.

Walstrom, J., (2004). The child with chronic pain. *Journal for Specialists in Pediatric Nursing 9,* 135 – 138.

Zeltzer, L., Bursch, B., & Walco, G. (1997). Pain responsiveness and chronic pain: a psychobiological perspective. *Developmental and Behavioral Pediatrics 18*(6), 413 – 422.

Zeltzer, L.K., Tsao, J.C., Bursch, B., & Myers, C.D. (2006). Introduction to the special issue on pain: from pain to pain-associated disability syndrome. *Journal of Pediatric Psychology, 31*(7), 661 – 666

Appendix 2: Survey and Parental information Letter

1. What is your child's date of birth?

   ____ Day ____ Month ____ Year

2. How long has your child had pain?
   - ☐ Less than 3 months
   - ☐ 3-6 months
   - ☐ 6 months – 1 year
   - ☐ 1-2 years
   - ☐ More than 2 years

3. On average, how often does your child have pain?
   - ☐ Every day of the week
   - ☐ 5 to 6 days per week
   - ☐ 2 to 4 days per week
   - ☐ 1 day per week
   - ☐ Less than one day per week

4. What type of pain does your child have? Check all that apply.
   - ☐ Headache
   - ☐ Abdominal pain
   - ☐ Muscular pain
   - ☐ Arthritis
   - ☐ Fibromyalgia
   - ☐ Complex regional pain syndrome (also known as RSD)
   - ☐ Other (please describe)

   _____

5. How many health professionals has your child seen about the pain?
   Physicians _____
   Psychologists _____
   Physiotherapists _____
   Acupuncturist _____
   Naturopath _____
   Others (please specify)
   _____

6. What is your relationship to this child?

   ☐ mother

   ☐ father

   ☐ Grandparent

   ☐ Guardian

   ☐ Other (please specify) _____

7. We would like to know your views about different types of treatment.

   We will use the numbers 1 to 4 for your answers where **1** means that it is *not important* to you and **4** that it is *very important*.

Please tell us how important it is for you to receive information about each of the following by circling a number from 1 to 4:

a. The cause(s) of my child's pain

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

b. Treatments that could be used for my child

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

c. Drugs to help the pain

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

d. Ways to cope with pain

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

e. Effects of pain on feelings or mood

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

f. Effects of pain on the body

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

g. Is there anything else you would like information about?

_____

8. The following questions are about the treatments given by the pain clinic. Please tell us how important each treatment is for you.

a. Receiving pain drugs

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

b. Receiving additional medical tests

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

c. Having physiotherapy

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

d. Getting counseling or psychological help

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

e. Getting reading materials about chronic pain

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

f. Being able to attend information sessions

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

g. Having the pain team be there for you

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

h. Having other parents be there for you

Not Important	Somewhat Important	Important	Very Important
1	2	3	4

9. Is some other treatment important to you? Please specify.

_____

Thank you for answering these questions.

Kathy Reid

INFORMATION SHEET

Title of Research Study: Treatment Expectations of Parents whose Children are referred to a Pediatric Chronic Pain Clinic?

Principle Investigator: Kathy Reid (University of Alberta)

Sub-Investigators: Dr. Janice Lander (University of Alberta)

What This Study Is About
Children who have chronic pain may be treated in a pain clinic. Canada has few of these clinics. We do not know much about the help parents might want. The purpose of this study is to find out what help parents prefer.

How We Do This Study:
You will be asked to complete some questions about:

- How important or unimportant it is for you to get information about chronic pain, and
- How important or unimportant various help is to you.

It will take a few minutes for you to do the study. You can do it in the waiting room. Although we hope you will be able to answer all questions, you do not need to answer all of them. You may leave any or all questions unanswered if you wish. When you are done, place the study form in the envelope, seal it and hand it back to the clinic staff.

By completing and returning this survey your consent to participate is implied.

If You Do Not Wish to Join this Study:
You can tell us that you do not wish to join the study.

You can also make sure that no one in the clinic knows that you do not wish to join the study. Place the unfinished study forms in the envelope. Seal the envelope and hand it back to the clinic staff.

Your child's care will not be affected if you join or do not join the study.

Your Privacy:
You will not be asked to write your name or your child's name on the study form. No other information that identifies you is on the study form. Your answers to the questions will not be included in your child's hospital records. Your name will never be used in any presentations or publications of the study results. All information will be kept private. The information that you provide will be kept for at least five years after the study is done. The information will be kept in a locked cupboard.

Benefits From Joining This Study:
You and your child will not benefit from joining the study. The information you give may assist health professionals to care for children with chronic pain in future.

If you have any questions about the study method, contact:

- Researcher, Kathy Reid, RN, Stollery Children's Hospital at 780-407-1363; or
- Supervisor, Dr. Janice Lander at 780-492-6317

If you have concerns about the research, contact:

- Patient Relations, Capital Health at 780-482-8080.

Statistics:

Fleish-Kincade reading ease = 73.2

Fleish-Kincade reading grade = 6.2

Fleish-Kincade reading statistics were obtained for the following information section of text from the consent form: